

### Subpart C—Discretionary Grants and Contracts

#### § 1340.20 Confidentiality.

All projects and programs supported under the Act must hold all information related to personal facts or circumstances about individuals involved in those projects or programs confidential and shall not disclose any of the information in other than summary, statistical, or other form which does not identify specific individuals, except in accordance with § 1340.14(i).

#### APPENDIX TO PART 1340—INTERPRETATIVE GUIDELINES REGARDING 45 CFR 1340.15—SERVICES AND TREATMENT FOR DISABLED INFANTS

**EXPLANATORY NOTE:** The interpretative guidelines which follow were based on the proposed rule (49 FR 48160, December 10, 1984) and were published with the final rule on April 15, 1985 (50 FR 14878). References to the “proposed rule” and “final rule” in these guidelines refer to these actions.

Since that time, the Child Abuse Prevention and Treatment Act was revised, reorganized, and reauthorized by Public Law 100–294 (April 25, 1988) and renumbered by Pub. L. 101–126 (October 25, 1989). Accordingly, the definitions formerly in section 3 of the Act are now found in section 113; the State eligibility requirements formerly in section 4 of the Act are now found in section 107; and references to the “final rule” mean references to § 1340.15 of this part.

This appendix sets forth the Department’s interpretative guidelines regarding several terms that appear in the definition of the term “withholding of medically indicated treatment” in section 3(3) of the Child Abuse Prevention and Treatment Act, as amended by section 121(3) of the Child Abuse Amendments of 1984. This statutory definition is repeated in § 1340.15(b)(2) of the final rule.

The Department’s proposed rule to implement those provisions of the Child Abuse Amendments of 1984 relating to services and treatment for disabled infants included a number of proposed clarifying definitions of several terms used in the statutory definition. The preamble to the proposed rule explained these proposed clarifying definitions, and in some cases used examples of specific diagnoses to elaborate on meaning.

During the comment period on the proposed rule, many commenters urged deletion of these clarifying definitions and avoidance of examples of specific diagnoses. Many commenters also objected to the specific wording of some of the proposed clarifying definitions, particularly in connection with the

proposed use of the word “imminent” to describe the proximity in time at which death is anticipated regardless of treatment in relation to circumstances under which treatment (other than appropriate nutrition, hydration and medication) need not be provided. A letter from the six principal sponsors of the “compromise amendment” which became the pertinent provisions of the Child Abuse Amendments of 1984 urged deletion of “imminent” and careful consideration of the other concerns expressed.

After consideration of these recommendations, the Department decided not to adopt these several proposed clarifying definitions as part of the final rule. It was also decided that effective implementation of the program established by the Child Abuse Amendments would be advanced by the Department stating its interpretations of several key terms in the statutory definition. This is the purpose of this appendix.

The interpretative guidelines that follow have carefully considered comments submitted during the comment period on the proposed rule. These guidelines are set forth and explained without the use of specific diagnostic examples to elaborate on meaning.

Finally, by way of introduction, the Department does not seek to establish these interpretative guidelines as binding rules of law, nor to prejudge the exercise of reasonable medical judgment in responding to specific circumstances. Rather, this guidance is intended to assist in interpreting the statutory definition so that it may be rationally and thoughtfully applied in specific contexts in a manner fully consistent with the legislative intent.

#### 1. *In general: The statutory definition of “withholding of medically indicated treatment.”*

Section 1340.15(b)(2) of the final rule defines the term “withholding of medically indicated treatment” with a definition identical to that which appears in section 3(3) of the Act (as amended by section 121(3) of the Child Abuse Amendments of 1984).

This definition has several main features. First, it establishes the basic principle that all disabled infants with life-threatening conditions must be given medically indicated treatment, defined in terms of action to respond to the infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration or medication) which, in the treating physician’s (or physicians’) reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions.

Second, the statutory definition spells out three circumstances under which treatment is not considered “medically indicated.” These are when, in the treating physician’s (or physicians’) reasonable medical judgment: